Maurice Abiven

Dying with dignity

People facing death because of incurable illness are likely to suffer intense physical and mental distress. The provision of help and support for them can be seen as a medical discipline in its own right, demanding special training and attitudes. Each country needs to work out the best ways of looking after dying people in accordance with its culture and resources.

An illness may reach a stage where no curative therapy is applicable and only palliative care is possible. Some physicians consider that the adoption of palliative care amounts to giving up the fight for recovery, but if nothing remains to prevent an illness from leading to death there is no ethical objection to discontinuing curative procedures.

In France about 540,000 people die every year, some 130,000 of them from cancer. A study in the USA indicated that 90% of cancer patients died when receiving palliative care (1). If we apply this figure to France, where medical practice is similar to that in the USA, it seems likely that about 117,000 cancer patients die each year in comparable circumstances. Of course, patients with AIDS and others receiving only symptomatic treatment at the time of death should be added to this number. The American study also found that the average life expectancy of cancer patients in the palliative phase of care was 94 days. In France this would suggest that about 120,000 dying patients should be able to benefit from palliative care for approximately three months annually.

The crisis of dying

Terminally ill people may undergo a range of symptoms. It is important to bear in mind that the thought of dying is the backdrop against which the final period is set. It should also be remembered that these people, although dying, are nevertheless living through a particular experience, unique for each individual.

The crisis of dying begins once the patient has accepted the imminence of her or his death. Withdrawal occurs, marked by indifference to certain previous interests
such as hobbies. In the very last moments the patient may be interested in only the very nearest objects, for instance the bed, and her or his own body and skin. This is why touching the outstretched hand is so important for maintaining contact with the patient as death draws close.

A comprehensive medical response is necessary because different symptoms tend to intensify each other.

However, some elements in the patient’s life may become more highly cherished. Most dying people feel a need for the presence of their closest relations. Everything should be done to make this possible.

The medical response

Once it has become impossible to stop the progress of an illness, the medical investigations into its course can be discontinued. On the other hand a meticulous record of symptoms must be kept. The patients should, as far as possible, be spared distressing radiological examinations and repeated blood tests. The physician needs to be a good clinician in order to care properly for the dying. Good clinical assessment of symptoms permits the best possible response to suffering. A comprehensive medical response is necessary because different symptoms, whether physical or mental, tend to intensify each other.

The physician’s task is to help the patient to live without too much distress. This requires careful assessment of the various kinds of symptom: physical, psychological, family-related, spiritual and so on.

Chronic pain, which occurs very often during the terminal phase of cancer, has to be alleviated before there can be any prospect of helping a patient in any other way. Dyspnoea can be most distressing and is sometimes very difficult to treat. Highly effective drugs are available for the treatment of digestive disorders, although treatment need not be purely medicinal. Some anorexias improve considerably when careful mouth care is given, while others benefit from attention to diet. For patients with a poor appetite who often have to eat mashed food, its attractive presentation on the plate is sometimes of the utmost importance.

In the interest of the patient’s comfort, wounds and bedsores should be properly dressed as often as required. A physiotherapist may be able to relieve the discomfort of ankylosis or restore some independence of movement.

As regards psychological and emotional symptoms, the first point to consider is the anguish that may be caused by the thought of impending death. Anxiolytics may be of value and the physician must know how to administer them. However, I believe that listening to the patient with empathy is even more important, and perhaps the best treatment for this symptom. Much time may be required because problems may be difficult to express. It should also be borne in mind that a patient in bed is more likely to speak freely to somebody seated than to a person standing up.

Psychiatric disorders in the form of delirious episodes, which may occur in the ultimate period before death, are not always the result of brain metastases. Sometimes it seems that they reflect evasion by patients
who cannot bear the idea of impending death.

In the social and family-related category of symptoms, suffice it to mention the numerous conflicts that may occur within families. It may be important to help dying people to resolve such problems.

For some people the end of life is a time for spiritual questioning, for considering the meaning of life, not necessarily in a religious sense. For instance they may ask themselves what use they have been. If a dying person has a religious belief, religion may help her or him to find answers. Ministers of religion certainly have a role in palliative care teams; in some circumstances they are the best people for the sick to talk to.

Some symptoms can be relieved relatively easily by means of ordinary symptomatic medicine. Others require the participation of people other than doctors: family members in particular, as well as social workers, lawyers, and ministers of religion. The aim is to help the sick person to live, something possibly involving activities that are rare in other situations.

**Ethical problems**

If it is impossible to halt or even delay the progression of an illness, it is logical to accept that the quality of life is more important than its length. In curative medicine, patients may be given examinations and treatments that impair the quality of life but extend its length. In order to relieve painful symptoms in a dying person, on the other hand, it may be reasonable to offer a treatment with possible side-effects that could hasten death.

In medical practice the patient’s choice should be respected. However, physicians may feel that they have a duty to try and influence their patients if, for example, a choice is made in ignorance of associated risks. Thus a patient’s refusal to rest completely after a myocardial infarction could have very serious consequences, and the aim of the doctor would be to prolong the patient’s life. But the values are reversed for people in the terminal phase of illness; if a person wishes to take an action that could shorten his or her life, for instance by going on a long journey, there is no longer any reason to advise against it. More commonly, why refuse to let a patient return home to die on the ground that this would prevent him or her from trying another treatment? In these cases common sense should lead to an ethical choice that runs contrary to habitual practice.

Similarly, not only curative but also palliative treatment may be stopped. For example, it would be wrong to make a terminally ill patient undergo treatment to correct hyperkalaemia, since the methods would probably cause more distress than the disorder itself. Towards the end of life it is sometimes reasonable to leave a symptom untreated even though the patient may die earlier than would otherwise have been the case.

One should guard against overzealous therapy: treatment out of all proportion to what one can reasonably expect to achieve.
Some intensive care specialists do not look at their dying patients with sufficient objectivity and continue to use aggressive therapies in an attempt to delay death at any price. It is worth noting that a patient’s family may criticize and perhaps even sue an intensive care unit on account of such therapy if the patient dies. If the patient survives, however, the treatment is likely to be praised as demonstrating admirable persistence.

In this connection the notion of a patient facing certain death is again crucial. If the patient has a disease that is inevitably fatal the rule about opting for quality rather than length of life should be applied and the patient’s wishes should be fully respected. This could conceivably mean turning off a life-support machine at the patient’s request. Often raised in such cases is the question of passive euthanasia. Is it a form of euthanasia to refrain from giving a patient treatment that could prolong life?

In the kinds of case that concern us here, it is not the acts of physicians that cause death but the illnesses from which the patients suffer. It should also be recalled that the

but I believe that ethical issues call for rigorous examination of the preciseness, meaning and implication of the terms used. Any other approach can only lead to vague guidelines that would leave physicians baffled in specific situations.

A medical discipline

A large number of dying patients need palliative care for quite long periods, during which various procedures relating to choice of treatment, psychological support, ethical options and so on have to be applied. All who look after the sick should be able to give this sort of care and should have the specific information and training that will enable them to do so.

Palliative care organizations have been holding conferences for over ten years and several specialist journals have been in circulation for almost as long. This seems to indicate that palliative care for the terminally ill is a medical discipline in its own right. It is the discipline concerned with the end of life.

Training

To ensure that the best possible care is given to sick people at the end of their lives, the staff involved should be given suitable training. Palliative care is not taught systematically in the majority of faculties of medicine and nursing schools. Only a few countries have included it in curricula. The teaching that is offered varies a great deal. Some faculties teach the subject from the outset, others offer it as an option after the basic course of study has been completed. In the majority of countries, trainee nurses receive a better introduction to palliative care and better teaching about death than do medical students.
An international congress on basic instruction in palliative care was held in Brussels in October 1991. Its findings should prove valuable in the preparation of curricula. However, even good basic teaching cannot solve all the problems faced by those who look after the dying. In-service training should help teams that take care of dying patients to maintain their technical skills at the highest possible level. Courses, lectures, study visits and participation in conferences should be encouraged so that team members can increase their competence in the new discipline. Particular difficulties are encountered in working with the dying (2, 3); staff who are continually confronted with death may suffer mental exhaustion manifesting itself as migraine, fatigue disproportionate to work, breathing difficulties, loss of appetite, and other somatic symptoms, or as anxiety, irrational fears and crying fits. In order to protect personnel they should be provided with the best possible information and should be given opportunities to exchange views at regular meetings. With a psychologist's help, team members should be encouraged to express their tensions, whether these stem from the team or from difficulty in relating to patients and their problems. Group discussion is particularly necessary in this endeavour. My experience of work in a palliative care unit where special attention was paid to preventing the suffering of staff convinces me that such protection can be completely effective.

Public awareness

The objective of helping the dying until life ends is attainable only if the general public understands the nature of the activity. It is not only hospital staffs who need to know when to stop treatment in order to allow patients to die with dignity. When the time comes, families too have to be able to accept that further treatment would be useless and that there are better ways of helping the dying than stuffing them with food or making them sleep at all costs. For death to be made as easy as possible the presence and help of family and close friends should be accepted. This contribution is most likely to be secured if the people concerned understand the objectives of palliative care and the way it is practised. Otherwise, when a patient ceases to receive treatment a particular family member may look on the situation as one of neglect. They may also fail to realize the importance of the dialogue that the hospital staff are trying to maintain with the patient in order to combat her or his anxiety.

Informing the public is not directly a matter for hospital staff but they can contribute in this area. The mass media should explain the nature of palliative care, its objectives, and the resources needed for achieving them. Voluntary associations can help to heighten public awareness through conferences and newspapers. In Europe there are many such bodies; some are very active and take part not only in informing the public but also in collecting funds to help with setting up or running institutions.

Institutional and socioeconomic factors

Does the care of the dying require specialist establishments? Should palliative care units be set up along the same lines as intensive
care units? Should specialist hospices for the dying be provided?

Many people evidently wish to die at home. But, at least in the industrialized countries, circumstances oblige patients to die in hospitals, retirement homes or other

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institutions. In France about 70% of deaths occur in hospital. Patients should be able to die where they were looked after during their last illness, and should be cared for by the doctors and nurses they know. This undoubtedly minimizes the psychological trauma for the dying.

Until the necessary changes can be made, we should create specific premises and specialist teams to provide palliative care. Depending on the country, the location and the administrative and economic resources, various solutions are possible.

Hospices were introduced in the United Kingdom over a century ago and have been considerably improved over the last 25 years. They are small hospitals with 30 to 70 beds where all the patients are terminally ill. Similar institutions have been established in Australia, Canada, Japan, and the USA. Another effective formula, now widely adopted, is to set up palliative care units in general hospitals. It has the advantages of not requiring new buildings and of keeping patients in the hospitals where they have been looked after, even if not in the same departments.

Yet another solution is to create specialist palliative care teams in hospitals, consisting of doctors, nurses, psychologists and social workers. At the request of staff they visit patients in the hospital departments to give advice or provide psychological assistance to patients or staff. This is a very flexible system and provides the staff in the departments with training in the care and support of dying people.

Other formulas may exist or will have to be developed so as to enable staff to look after the dying in the manner most appropriate to local sociological and economic circumstances. Since administrative and economic structures vary so widely it is difficult to suggest changes in legislation that would facilitate the creation or development of palliative care. Each country needs to work out the best possible way of looking after its dying in relation to its medical development, hospital system, welfare facilities, customs, and family and religious structures. Some general points are, however, worth making.

If dying patients are being cared for at home the activities of the professionals looking after them should be coordinated. It is not desirable for the physician, nurse, physiotherapist and social worker to visit patients in a totally unplanned manner. This can lead to insecurity and anxiety on the part of the patients and their families. In some countries, coordination in this matter has already been achieved, either hospital-based or in the form of multidisciplinary teams linked by nurse coordinators. The experience gained now seems sufficient to provide others with a model to be copied or used as a guide.

Hospital systems and internal hospital regulations vary so much from country to country that it is not possible to suggest changes in regulations that would be
universally useful. However, in so far as terminally ill patients have specific needs, consideration should be given to making some alterations in the way hospital departments operate. Since the presence of close relatives is very important, it is desirable to accommodate them properly and to modify visiting rules so that they can spend as much time as they wish with patients. It is also a good idea to regroup terminally ill patients so that nurses can spend more time with them than with other patients.

Specialized departments for palliative care, designed to accommodate the dying and staffed by appropriately trained people, will undoubtedly long remain ideal training grounds for medical and nursing staff. Through the quality of their work they will also help to show the public that the hospital and its staff can render a great service to the dying.

Cost

It is extremely difficult to assess the cost of palliative care for the terminally ill. Indeed, the differences in the ways social and hospital services operate in different countries are too great for cost estimates to be of any value.

Palliative care, although requiring lower technology than other branches of medicine, is nevertheless costly because it demands comparatively large amounts of staff time. A study at the International Hospital in Paris showed that the cost of a day in the palliative care unit was similar to that of a day in a department for acute conditions. However, this is practically meaningless, since no account was taken of the changes that palliative care would produce in the lengths of hospital stays and so on.

For death to be made as easy as possible the presence and help of family and close friends should be accepted.

In my view, public authorities should not appraise the care of the dying in terms of health economics. If it is accepted that such care improves the final stage of life for many people, the authorities should endeavour to make it available in the most appropriate manner in each country.

References


Discussion

Vittorio Ventafridda

— At home or in hospital?

In a recent survey (1) in Italy, healthy individuals were asked whether they would prefer to die at home or in hospital if they became terminally ill; more than 64% expressed a preference for dying at home. A survey of terminally ill patients also obtained a similar result (2).

Unfortunately it commonly happens that patients’ wishes are not taken into consideration. Indeed, it is easier to overlook them under the false conviction that treatments, either for managing or fighting cancer, can only be administered in hospital. In the final months of life, moreover, patients are submitted to an increased number of surgical and exploratory diagnostic procedures, resulting in a tremendous waste of resources. The higher the social status of the patient, the greater is the tendency to prescribe useless treatments with a view to improving the quality of life.

By contrast, patients of lower social status are often confronted with abandonment or indifference by carers at home or in hospital. Poor health education and inadequate palliative care condemn most terminally ill people to death without dignity in obscure hospital wards. An additional problem is that most health care professionals are reluctant to use methods for mitigating pain which might be interpreted as amounting to euthanasia.

Most members of the general public believe that the feelings and wishes of patients should be respected. Dr Abiven makes the point that a treatment should not be given to a terminally ill person if it is likely to cause worse distress than the disorder being suffered. Physicians play a decisive role in assisting the dying to fulfil their wishes. Some intellectuals and health care professionals seem to place more emphasis on the desirability of legalized euthanasia than on palliative care. The confusion surrounding these matters, the scarcity of dedicated health care personnel, and the lack of information on the use of analgesic opioids mean that much remains to be done in health education.

Today, intensive treatment for cancer virtually isolates many patients and forces them to die in hospital. Yet hospitals can do a lot for them by allowing free access for family members and loved ones and by creating a warm, comfortable environment in which patients are assisted by trained staff, as happens in hospices. Clearly, if patients do not have close friends or relatives to take care of them, or if they are functionally handicapped, they are ultimately obliged to die in hospital.

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The best place to die is at home. Hospitals and health care centres can be excellent coordinators of direct assistance in home care. The patient’s home is likely to be a place where the entire family can show love, compassion and caring. However, this demands a social system that allows family members to care for very ill patients. There is also a need to organize local volunteer groups to work in tandem with physicians and nurses.

The roles of home-care providers and the balance between private and public assistance, integrated with the support of volunteers and other services, have to be defined. Home-care volunteer groups have been shown to benefit patients and their families significantly and to improve the attitude and behaviour towards terminally ill people of health care professionals.

The last phase of life of a person who is dying can be made easier at home than in an institution, irrespective of the clinical situation, provided that all the necessary equipment is available and that the correct information is given to the patient’s carers. The support of volunteers, social workers or clergy becomes increasingly important as the end approaches, for both the dying person and his or her family. People are helped to die with dignity if they are in an environment where they have experienced happiness, affection and family life. This is why it is so desirable for people to have the possibility of dying in their own homes or at least in personalized hospital rooms with the assistance of trained carers.

Stein Husebø

— Palliative care should be integrated into all aspects of medicine

The subject covered by Dr Abiven is of considerable interest in Scandinavia, where health care is highly developed but systematic medical education and training in palliative care are still lacking. Hospice teams are being established in many hospitals and the hospice philosophy is increasingly influencing the health care systems. At present, approximately 80% of patients die in hospitals but this situation is gradually changing.

The home care services are extremely well developed and there is a widespread conviction that the best place for a cancer patient to die is at home. Models for palliative care in the home are being established.

Resources are being put into the education of health professionals in palliative medicine, and endeavours are being made to integrate palliative care into all aspects of medicine. Modern standards of pain treatment and symptom control are familiar to most Scandinavian doctors and nurses, and useful guidelines are available in all the region’s languages.

The best place for a cancer patient to die is at home.


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Efforts are being made to give information directly to patients and their families in the form of books and brochures written specifically for them. The knowledge arising from experience in palliative medicine should be communicated to other fields, including acute medicine.

Although fewer than a third of patients die from cancer, cancer patients receive a far higher standard of palliative and medical treatment than does the average person who is dying. It is to be hoped that the quality of care given to cancer patients will be more widely available in the future.

Neil MacDonald

— Avoid separating palliative care from the mainstream of medical practice

The palliative care movement emerged in response to poor treatment given to dying patients. Cancer patients were singled out for special attention because of the prolonged physical and psychosocial distress they commonly suffer prior to death. The tenets of palliative care, however, are readily translated to other settings, including programmes for people with AIDS, many of whom have similar patterns of symptoms to those experienced by patients with advanced cancer.

As Dr Abiven points out, palliative medicine is taking on the mantle of a separate medical discipline that is particularly concerned with cancer patients during the last 100 days or so of life, and their families. This move is positive in that it should improve standards of care, the morale of palliative care workers, and the education of health professionals. However, if palliative medicine is isolated from the oncological disciplines, there is likely to be a break in the continuity of care and a failure to introduce palliative aspects of care early in patients’ illnesses. One should also guard against identifying palliative care exclusively with cancer, since this could limit its application to other chronic, ultimately fatal illnesses.

The prevention of suffering can be seen as the fourth phase of cancer prevention (1), following primary disease prevention, early detection and treatment. There are very practical reasons for this. The psychosocial and physical problems of the dying are heavily influenced by the care patients and their families receive earlier in the course of illness. A brusque approach to psychological distress at the time of diagnosis or early treatment results in major problems at a later stage (2). Unresolved pain causes changes in neural sensory circuits which accentuate pain and may create a neuropathic component that is very difficult to treat. Early skilful management of cancer pain should diminish pain and increase the effectiveness of therapy in the last days of life. In animal systems it has been shown that chronic pain reduces the immune tumour response. (3).

Palliative medicine should develop as an integral part of cancer care. For some time to come most cancer patients can be expected to die of their disease; cancer centres should recognize and provide for the needs of this large segment of the patients under their care.

Advanced cancer patients should receive most of their care in their homes. If cancer centres have palliative care teams they should readily collaborate with similar

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groups based in community hospitals, hospices or in home care organizations. Practitioners in the latter settings may come to palliative care through general practice or other professional backgrounds and may be more involved with patients suffering from other chronic illnesses. As the principles of palliative care are essentially those of humane medical practice, there should be a great diversity of professional pathways leading to specialization in this field.

Palliative care has been given little attention as a component of AIDS programmes. This is reminiscent of the early history of cancer care, when research was related wholly to prevention and treatment despite the ultimate fatal outcome of the disease in most patients. AIDS journals are replete with articles on epidemiology, pathophysiology, infectious complications and antiviral therapies, but place much less emphasis on palliative care.

The lack of coordination between palliative care and AIDS programmes in the West should not be repeated in developing countries. Where cancer patients present in the late stages of their disease and AIDS patients have little access to sophisticated anti-infectious therapies, simple palliative care programmes should be created to assist both groups and their families, and perhaps people affected by other chronic conditions. As with cancer the early application of palliative therapies should benefit AIDS patients throughout their illness. The emerging treatments for cachexia may be particularly important.

As Dr Abiven says, each country needs to work out the best ways of looking after dying people in accordance with its culture and resources. Palliative care involves inexpensive therapies and simple training and does not substantially deplete other health resources; it should develop in a complementary rather than a competitive manner.

A palliative care curriculum has recently been designed for integration into an undergraduate medical course in Canada. The principles of palliative care are the same as those of good general medical care. Pain control and an understanding of social and community issues are important in obstetrics, orthopaedics and other medical disciplines, as well as in palliative care. The palliative care movement can help to reinfuse medical practice with humanism.


Ian Maddocks

— Teamwork among carers is essential, for both them and their patients

Ideally, patients undergoing terminal illness should receive consistent, comprehensive care that encompasses the full range of their needs and those of their families, and it

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should be delivered where it is most convenient for the patients.

The clinical judgement that no further intense efforts at cure or palliation are appropriate is often made at a major hospital. In this circumstance it often seems best to send the patient home if the community care service offering home supervision and a hospice inpatient facility, each having its own palliative care team, it is preferable to have a single team with acknowledged authority and responsibility in all these areas.

Training in palliative care should emphasize the elements of knowledge on which a rigorous assessment of symptoms depends and an effective plan of management is based. However, it should also address the broader skills used to elicit and meet families' emotional needs, and encourage team members from different backgrounds to appreciate and share the attitudes, insights and expertise which they possess.

Each has a specific contribution: the doctor in diagnosis and prescribing; the nurse in the many bedside manoeuvres that augment comfort; the psychologist or social worker in helping to ease emotional tensions and clarifying dilemmas; the volunteer in attending quietly and offering the precious gift of time. But there are common features too, founded on a commitment to care, a determination to see that no part of the journey for the patient and the family involves needless suffering, a willingness to try again if a measure fails.

There is merit in a training programme that brings various categories of health worker together and encourages commitment to process as well as to factual knowledge, to cooperation as well as to clinical skills. Each profession has its own training requirements and its criteria for an additional qualification, and sometimes a definitive specialist programme for the physician or nurse is necessary. But there may also be opportunities in undergraduate or postgraduate courses or in-service education to train the different categories together and encourage them not only to improve their own special skills but also to help the
development of each other’s contributions to comprehensive care.

The demands on people who look after patients with terminal illnesses are great. The clinical situation changes continually, emotional crises occur, family members seek more attention than can reasonably be offered. Staff may therefore tend to give more and more of themselves. They usually derive great joy from working closely with family members, and they are the subjects of many heartfelt expressions of thanks and praise. But they may easily become physically tired and emotionally strained, as Dr Abiven makes clear. For a small team with good internal communication whose members are mutually caring, stress can be minimized. However, if dedication is absent, if individuals feel isolated, unsupported or unrecognized, and if bureaucratic requirements seem to take precedence over the care of patients, staff stress and burn-out can be expected. As Dr Abiven says, it is possible to protect personnel, particularly through group discussion.

Palliative care transcends the traditional barriers that tend to keep hospital care separate from community care, give the skills of doctors precedence over those of other health workers, and lead to the training and deployment of the different professional categories as separate entities. It is winning wide recognition for excellence and is bringing forward new philosophies and attitudes which may change the face of medicine.

Anneli Vainio

— Must dignity decline as development proceeds?

Globally, about 50 million people die every year, some 11 million of them in the developed countries and 39 million in the developing countries. In the 33 most developed countries, mean life expectancy at birth is around 74 years, ranging from 79 years in Japan to 68 years in the USSR (1). Women, on average, can expect to live 77 years, more than three years longer than men. In the industrialized countries, two-thirds of deaths occur in people aged at least 65 and are attributable to chronic diseases. Under 3% of mortality occurs among infants, and their deaths are mostly due to perinatal and congenital conditions that are very difficult to eliminate.

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Over half the deaths in industrialized countries are related to cardiovascular diseases. Cancer is the second most important cause, accounting for 20% of mortality, lung cancer being the outstanding disease in this respect. Clearly, in the developed countries the leading causes of death are conditions largely connected with personal life-styles.

By contrast, in the high-mortality countries of Africa and Asia, life expectancy at birth is only 53 years; more than 20% of children die before they reach the age of 5 years (2). Diarrhoeal diseases, measles and respiratory infections, often aggravated by malnutrition, are the main causes of childhood mortality. In adults, tuberculosis is one of the most important infections. The high mortality rates associated with infectious disease reflect unsafe water and food supplies, poor housing, difficult or no access to health services, poor education, uncontrolled population increase, and other determinants of poor health status.
More than half the world’s cancer cases occur in the developing countries, yet less than 10% of the resources allocated to cancer control go towards helping the people affected. Late diagnosis and incurable disease are frequent in these countries; good symptom control and palliative care are urgently needed in order to relieve suffering.

Dr Abiven describes very well the basic principles of palliative care. Some of his suggestions, however, while relevant to the developed countries with their well-equipped and adequately staffed hospitals, scarcely apply in the developing countries. For the majority of the world’s cancer patients, excessive curative treatment and uncoordinated visits by physicians, nurses, physiotherapists and social workers are not a problem.

In Finland, where more than 90% of cancer patients die in well-equipped hospitals, 550 family members of deceased cancer patients were questioned about terminal care in these establishments (3). It emerged that 74% of the patients had suffered pain and that this had lasted several months in two-thirds of the cases. Less than half the respondents said that the patients had had adequate psychological support from hospital staff, physicians having given less support of this kind than nurses. The profound

Furthermore, in many cases the hospital routine had prevented family members from staying long enough with patients. Dying in hospital in Finland mirrors the general attitude towards death in Western culture. In many countries, death has been removed from homes and families to highly specialized medical centres. The medicalization of dying has taken away its sociocultural meaning and reduced it from being a major event in life to a purely biotechnological event.

In Tanzania, society has chosen a different way of coping with death. While dying is not seen as a natural part of life, as in the West, death is dealt with on a broader social basis and the bereaved receive collective support. Numerous relatives, friends and neighbours of a deceased person come together in mourning. A bereavement period of 40 days then begins, during which work and sexuality are taboos for the people concerned. This situation, in which family members and friends are present and rituals are repeated, has much in common with modern crisis therapy. At the end of the bereavement period a joyful celebration is held.

Even in the West, death had more sociocultural connotations a few generations ago than it does today. Grandparents died at home, often surrounded by their children, relatives and friends. Communal singing and praying formed the cultural framework for dying. When death was approaching, relatives and neighbours came to say goodbye and, if necessary, effect reconciliations. Deceased persons were washed, changed into their best clothes, laid out among flowers and candles, and visited by many people.

These practices have largely been forgotten in the West, and many people have neither seen a dead person nor participated in a
funeral. One of the tasks of palliative care in the West, therefore, is to bring back to dying some of its meaning and dignity. In many developing countries, collective habits and rituals are still strong and help the dying and bereaved through a difficult time; the great task of palliative care in these countries will be to relieve pain.  


Kjell Pedersen  
— The will to live and die with dignity merits more than technological support

My wife, Inger, fought cancer for over 20 years. During this period she went through several severe crises when her doctors, having failed to appreciate her will to live, were not optimistic about her chances of survival.

The Norwegian Cancer Society had brought together a group of women who had had operations for breast cancer and were willing to visit others who were still in hospital after being operated on. The visitors made the point that to have cancer was not the end of the world and that survival was possible. Inger joined the visitors’ service. As her resources diminished it became physically hard for her to visit patients. Yet the fact that she could instil courage in others filled her with joy; this was something that could be done only by people who had been through the operation.

I believe that my wife received adequate medical treatment. In contrast, however, the family was given virtually no advice, information or social support. Inger spent only a small fraction of her time in an institution; mostly the family had to cope at home. We were not begging for assistance or totally helpless, but there was a striking contrast between the expertise in the hospital and the vacuum we felt we were in at home.

Our experiences bear out much of what Dr Abiven has to say about meeting not only medical but also emotional needs. The quality of life of the terminally ill and their families can undoubtedly be enhanced if humane advice and help are available. For instance, what does one say to young children when their mother has cancer? Does one play it down or go to the opposite extreme and tell them that she is dying?

In the army I had learned how to handle crises — by pulling yourself together and tackling the situation without losing your head. However, the first time my wife was sent home after a serious operation we were told it was successful and nobody warned us that she was close to panic. We had cleaned and prepared the house as best we could, yet she broke down hysterically and screamed that she was surrounded by squalor! This was her reaction to seeing a speck of dirt on the wall. Out of pure frustration, I smacked my young son for dirtying the house although he had nothing to do with it. Only

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later did we realize that my wife’s reaction had been caused by fear and physical exhaustion.

The impact of her mood changes, which are natural in someone who is fighting a serious illness for years, was hard for the family to bear. I could rationalize the situation and accept it without arguing or talking back, but it was very difficult for the children. It was as if the family had to play the main parts in a drama without guidance or rehearsals. Initially, I was like a rock while the other members of the family broke down in tears. Eventually my wife reacted by accusing me of not caring about her. It was a huge relief to her when she first saw me weep.

Inger maintained her will to live by becoming involved in things that had meaning for her. She participated in seminars and congresses, explaining to doctors and nurses what it was like to be a cancer patient. The professionals appreciated this because it helped them to understand what patients thought and felt. She was interviewed on radio and television. She also gave herself short-term goals: she wanted to live until our son had finished his university education and she did not want to give up when there was a possibility of her becoming a grandmother.

Whenever new pains or other symptoms appeared we felt an uncertainty in her until she knew what was happening. Then she became calm again, even though she realized that her condition was worsening. Frustratingly, it seemed impossible to obtain information we could understand from the professionals. A turning point came following a major operation. We were given the usual unclear, noncommittal explanations from the doctors. But on visiting the hospital I happened to meet a friend, a woman surgeon, who had assisted with the operation. She started weeping and I saw that things were serious. It emerged that the surgeons had found the cancer to be widespread and inoperable. The doctors estimated that she would live a few months, yet she actually survived for ten more years.

Somehow I developed a sort of conviction that she was not going to die. However, as the disease advanced she often talked about a time in the future when she would no longer be present. It was a theme that the rest of us wished to avoid but had to face. Eventually, when the treatment she was receiving was no longer having much effect, we were asked to give our opinion as to how to proceed. It would have been easy to say that she should continue with the treatment regardless of its side-effects, but I did not do so. I and the children said that she should make the decision. This she accepted but I think she found it hard that nobody strongly suggested continuation of the treatment at any cost. What really decided the matter was the absence of any short-term goals in view.

She took the decision not to have further treatment in hospital, and began planning details of her funeral and the practicalities of the lives of her husband and children once she had gone. She wanted to die at home. Initially I felt uneasy about this, fearing she would suffer a painful death for want of proper attention.
However, staff from a newly opened pain clinic came onto the scene. Its chief medical officer there had qualities beyond his technical abilities. I was given a full account of what was going to happen and the social services provided technical aides. So I took on the role of cancer nurse. The fact that I could contribute something useful gave me a very good feeling. But most importantly, my wife was in her own living room and she met her fate with equanimity, her spiritual strength intact until the end.

Rihito Kimura

— The right to be informed: an aspect of dignity

In Japan, a majority of people end their lives in hospital, surrounded by high-technology equipment. Yet in a recent survey over half the respondents said they would prefer to die at home. There has been a tradition of not explaining to terminally ill people the true nature of their condition, on the ground that this is the kindest way to proceed. However, views about this matter are changing. In a recent nationwide opinion poll (1), 65% of the participants said that if they were terminally ill they would like to be given full diagnostic information about themselves. Only 22% of the people questioned, however, said they themselves would definitely be prepared to disclose such information to a member of their family.

The same survey indicated that 78% of people considered palliative care desirable, even though it might shorten life; 16% thought life should be sustained as long as possible, irrespective of the pain that patients might be suffering.

The National Matsudo Hospital is one of the few hospitals in Japan with a palliative care unit. The use of morphine has significantly reduced pain levels for a high proportion of the patients in this establishment; in 1987, 75% of cancer inpatients were given end-stage fluid therapy but in 1990 the proportion had dropped to 12.5% because many families realized that the treatment shortened patients’ lives.

A special task force on terminal care, set up by the Ministry of Health and Welfare, issued a report in 1989 which encouraged the disclosure of diagnostic information to patients, provided that consideration was given to patients’ life histories, personalities, relationships with family members, and other factors. The use of drugs for pain control was favoured, and the report also dealt with various additional matters touched on by Dr Abiven, including spiritual requirements and the care of family members.

The view is gaining ground in Japan that people should not have to accept without question the authority of doctors in the treatment of disease. Unfortunately, there are still too few trained people to cope with the many problems associated with dying. Responsibility for the care of the dying

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should be shared between health professionals and other carers. Changes are needed in the mentalities of both health care providers and patients, and it has to be recognized that medical systems and institutions are not immutable.

Efforts have been made to improve the care of the dying by some volunteers and hospitals in Tokyo, Osaka and elsewhere.

There are signs of public approval for such work and the government has begun to provide financial support for palliative care through the national health insurance system.


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Molly Eriki

--- Counselling helps to achieve peace of mind ---

People who discover that they have HIV infection may become lonely, frightened and ashamed of themselves. Furthermore, a fear of death and a lack of knowledge about AIDS may cause the relatives of HIV-infected people to have negative attitudes towards them, to leave them on their own, and to ignore some of the caring for the sick need to be revived if terminally ill people are to be properly looked after. Such people need love and hope; it is important that they should not feel deserted or rejected. Relatives and communities should be understanding, forgiving and never judgemental. As Dr Abiven makes clear, support for dying people from families and community organizations is immensely valuable.

Counselling helps patients to accept their situation and achieve peace of mind. It removes feelings of hopelessness and imbalance. The counsellor can be seen as a friend who helps patients to explore all aspects of their problems. If, for example, patients are subject to opportunistic infections, help should be given in obtaining appropriate drugs. If a patient is neglected or abandoned by relatives an attempt should be made to counsel them, provided that the patient agrees. The relatives of dying people should be encouraged to give them all possible love, care and companionship. It may also be comforting for the terminally ill to be advised or reassured about questions of inheritance, the care of surviving children, funeral arrangements, and so on. It sometimes happens that, as a result of counselling, people with AIDS undertake to serve as counsellors themselves on, for instance, the prevention of HIV infection.

The relatives of dying people should be encouraged to give them all possible love, care and companionship.

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Interestingly, in some African societies it is believed that the spirits of people can return to torment relatives who have failed to care for the dying. It is also believed that a departing soul is capable of cursing and destroying people if dissatisfied with the treatment a dying person has received.

In most communities, people turn to God when problems arise. As death may come without warning, perpetual spiritual readiness is often thought prudent. People with AIDS and others facing death may obtain peace of mind through the offices of a religious leader, who may encourage them to accept God, pray and ask for forgiveness, and may convince them that there is life after death. Prayer gives hope and comfort, and to this end frequent pastoral visits by religious leaders, and group prayer involving both the dying and their relatives, are desirable. Religious music may also help people to die with dignity.

Li Tong-Du

— There is no dignity in trying to cure the incurable

In China over a million cancer patients die each year but only a small proportion of them receive palliative care, for reasons of finance, medical development, and culture.

In 1987, the country’s first hospital specifically designed for advanced cancer patients, with 500 beds, was opened in Anhui Province. Subsequently, numerous small hospital-like establishments for advanced cancer patients have been opened throughout the country, but the number of beds is far from adequate to meet the demand.

In rural China the overwhelming majority of cancer patients wish to die at home, and, indeed, the final period of their illness, lasting up to several months, is usually spent there. In general hospitals, incurable patients are usually not accepted, and the number of specialist hospitals is relatively small. With the exception of minority nationalities, the law requires that the remains of patients who have died in hospital be cremated, but this is not readily accepted by most rural people. Autopsy is widely considered obscene and unethical. Hardly anyone is prepared to leave their remains for medical research or organ transplantation.

In the cities, terminally ill patients commonly die in hospital, especially if they have access to free medical services. However, their carers, for the most part, have not had special training in palliative care.

In China, the dying receive the greatest possible sympathy and support from family, hospital, workplace and society in general. Every effort is usually made to prolong life. Traditionally, patients and the people around them have usually wished to use every possible means of conserving life, even in cases of incurable illness. This has led to aggressive therapies being continued.
until life ends in a simple attempt to delay death, regardless of the cost and the prolongation of suffering.

The points made by Dr Abiven concerning public awareness are certainly valid in China, where it needs to be heightened with respect to the nature and importance of palliative care for advanced cancer patients. The mass media and the specialists engaged in palliative care can both help this process. People should realize that the aim of palliative care is to help the dying and ensure that they die as easily as possible. The public should be encouraged to accept that curative treatment needs to be replaced by palliative care once it is clear that a disease is incurable. The alternative is to increase suffering and waste.

China needs more palliative care units, whether independent hospices or departments of hospitals, for patients who are not willing to stay at home. And a large number of doctors and nurses, trained in palliative care, are needed to ensure that patients with advanced cancer are looked after in the best possible way. Palliative care has not been included in the curricula of most of the country's medical colleges and nursing schools. The introduction of this subject should be treated as a matter of urgent necessity.

surrounded by loving relatives and friends. Perhaps this was only an illusion created by artists and writers. In the developed world, the present interest in dying with dignity is partly due to the increase in the number of cancer patients who are terminally ill but is mainly a reflection of the so-called progress in radical surgery, polychemotherapy and radiotherapy, which very few cancer patients now escape. These procedures have contributed to making the lives of terminal cancer patients anything but dignified.

Greater efforts should be made, on a long-term basis, to diminish the destructive nature of the initial stages of cancer treatment, so as to minimize the consequences that have a direct bearing on the quality of life in the later phases of the disease. Unfortunately, many cancer therapists consider that cure demands radical treatment and so their conversion to an acceptance of less damaging methods is unlikely to be easy.

Relatively few terminal patients in Europe are able to die at home surrounded by members of their families. The absence of familiar faces and the impression of being abandoned by loved ones accentuate feelings of isolation, loneliness and bitterness. Pain relief and palliative care cannot totally compensate for this. As Dr Abiven points out, dying with dignity has important social and spiritual components.

In Africa, the manner of dying is strongly influenced by socioeconomic, educational and, most importantly, sociocultural and spiritual factors. Dying, as well as being a biological phenomenon, is also a spiritual and cultural event.

The socioeconomic and educational situation in most African countries is such that there are very few hospitals and health services available for the vast majority of rural dwellers. Less than 20% of cancer patients

V. Anomah Ngu

— Spiritual considerations are all-important

A century ago in Europe, dying was frequently depicted as a dignified event, taking place in the patient's own bed

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enter hospital soon enough for curative treatment to be possible. Palliative care and pain relief with opiates are generally difficult to obtain for economic reasons. Catheters, tracheostomy tubes and other simple items needed for the relief of distressing symptoms are not available or are beyond the financial reach of patients in a system where cost recovery has been imposed by international monetary organizations. European suppliers of opiates have refused to send further consignments because previous bills have not been paid. The unavailability or high cost of drugs and facilities mean that most initially curable people fail to receive adequate treatment. Consequently, over 90% of cancer cases are terminal. The regulations governing the use of opiates for the terminally ill should be revised so that these drugs, if available, can be obtained by patients. Only concerted action by WHO and the International Narcotics Control Board in Vienna is likely to persuade African governments to effect the required changes in their laws.

The subject of palliative care should be covered in the training of doctors, nurses and other health workers so that the vast experience acquired in this field in Europe can be used to benefit African terminal cancer patients. The public clearly needs to be educated first on cancer and then on the needs of terminal or advanced cases. Fortunately, many African countries have already created organizations in which the public participate to fight cancer.

Cancer, especially if terminal, can inspire fear; this is tempered in traditional African societies by a firm belief in life after death with loved ones and by support derived from the strong family ties that still exist in rural Africa and to some extent in urban areas of the continents as well. Traditional Africans tend to have spiritual and moral, rather than material, preoccupations as death approaches. These concerns may relate to family relationships, the fulfilment of requests made by deceased relatives, and so on. Such preoccupations can be resolved in many cases through rites and rituals performed by patients or their families.

Death can then be awaited in an atmosphere of confidence and some tranquillity, and this helps to blunt physical suffering.

The complex ceremonies and rituals of mourning help to give those awaiting death a feeling of solidarity and love with their families and to reinforce the patients’ self-esteem. Such spiritual considerations confer dignity on the dying, and this is why terminal cancer patients in Africa are often discharged from hospital and taken home by their families.

Pinit Ratanakul

— For Buddhists it is vital to preserve full consciousness in the final stage of life

As Dr Abiven says, dying persons need to have special care that accords with the cultural resources of the society to which they belong. Each society considers the

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process of dying to be of great importance and has its own ways of coping with it. In Western culture, for example, as pointed out by Dr Abiven, treatment for the dying mostly involves medical, psychological and sociological care. The main concern of health care professionals in this culture is to alleviate the suffering of the dying and their families and to ensure that death occurs without severe pain; this, in the West, is what is regarded as dying with dignity, in the sense that dying people are not regarded as machines, nor sustained at a meaningless level of existence, perhaps for purposes of study or as organ banks.

In Buddhism culture, permeated as it is by Buddhism, more is required than loving care, humane maintenance, and medical treatment. Buddhism sees life and death as but one phase of an endless process. Death is considered the culmination of an existence filled with sorrow and suffering. The tragedy of death is magnified by the certainty of rebirth and the repetition of suffering and death. The ultimate aim of Buddhism is total deliverance from this cycle of life and death. To enable the dying to attain this goal, spiritual care is given to them; this means maintaining the dying at a level of pain relief that does not impair their faculties and consciousness. Dying persons who are committed to Buddhist teaching are thus enabled to raise their level of consciousness from ignorance to knowledge, through insight and awareness, so that the self and its aggregates are seen in their true state of impermanence, unsatisfactoriness and unsubstanciality. This awareness also leads to an apprehension of the causal chain of dependent origination, i.e., the fabric of causes and effects in the round of existences, and of the way to break this chain. Through such apprehension the “I”, the root cause of rebirth, is dissolved, like a light going out for want of fuel. This is brought about solely through the transition from ignorance to knowledge. Ignorance acts on the “I” as an identical and unchanging pole of craving and grasping force; whereas knowledge acts on the “I” as “not-I”, a transient phenomenon subject to impermanence, unsatisfactoriness and unsubstanciality. With the dissolution of the “I”, the grasping force which attracts to itself another existence is gone.

For Buddhists the keeping of their consciousness unimpaired by analgesics and sedatives enables them to fill their minds with wholesome thoughts. In Buddhist understanding the last conscious state of the dying is the most forceful. It can give a special characteristic to the resultant (rebirth) consciousness in another life. Even though the character of the new life is affected by the whole previous life, the nature of the last conscious state nevertheless contributes significantly to the quality of the ensuing one. If it is wholesome, this produces a wholesome inauguration of the new life.

Buddhist spiritual care for the dying is reflected in rituals and symbols. One important ritual is the reciting of a passage from the Bajjhanga, the purpose being to assist the dying Buddhist to become fully conscious so as to be able to:

- see the impermanent, unsatisfactory and unsubstantial nature of existence;
- think of his or her past good efforts (e.g., the practice of morality, charity and meditation);
— fill his or her mind with this wholesome thought;
— feel peace within him- or herself;
— be in deep meditation (serenity);
— let go of life without clinging and grasping.

Another important ritual consists of putting a Buddhist image before the dying and/or asking them to repeat the sacred word “Buddha” as a symbolic way of taking the Buddha as a refuge. The main purpose here is to boost the self-power of the dying so as to minimize their psychological trauma and permit them to die a “good death”, meaning death without rebirth or with a good rebirth.

Thus the Buddhist faith encourages all efforts to promote physical, psychological, social and spiritual care of the dying, particularly with a view to preserving full consciousness in the last stage of life, since this permits them to practise their religion either by meditation or by filling their minds with wholesome thoughts.

David J. Roy

— The care of dying people should match their changing needs

Dr Abiven observes that some physicians believe the adoption of palliative care amounts to giving up the fight for recovery, and he asks whether withholding or withdrawing life-prolonging treatment is a form of euthanasia. “Dying with dignity” has become a slogan of opposition to the degrading and useless prolongation of life that may occur when people are still minimally functional but can no longer exercise intelligent control over what happens to them. In the context of today’s medical technology, dignified dying calls for decisions that have both technical and ethical components. The kinds of decision that have to be taken provoke controversy and reveal strong tensions between people of diverse moral perceptions and persuasions. Judgements have to be made about what should be done to help people to live or die in a fashion that respects their dignity. The decisions are bounded by the unique biology, clinical condition, needs, desires, life plans, hopes, sufferings, strengths and limitations of each gravely ill person. There can be little place for absolutist thinking in this area. Judgements on the quality of life are inescapable because physicians and treatment teams are ethically required to measure the consequences of their work on the bodies and biographies of the people they are trying to help.

Doctors, nurses and families are increasingly forced to question the extension of life at all costs and the desirability of unrelenting treatments, particularly those of a physical, emotional and personal kind that the patient cannot bear. The view gaining ground in many countries is that it is not right to prolong life when it is little more than an
unbearable dying process as far as the patient is concerned.

In the course of illness a moment may arrive when it is no longer possible to restore health, function or consciousness or to reverse the dying process. In such a situation it is generally wrong to pursue aggressive curative treatment and it is ethically justifiable to allow a patient to die.

Helping a patient to die with dignity involves more than decisions about discontinuing life-prolonging treatment. True palliative care is the art and science of matching care to the dying patient’s changing needs. An essential element of dying with dignity is freedom from pain that can prevent people from thinking, expressing themselves and, indeed, doing things they want to do before they die. The ethical distinction between killing pain and killing the patient is clear. If life is shortened as a result of analgesic dosages required to relieve pain, death cannot be said to occur because of an overdose. Quite simply, the patient can no longer sustain the therapy required for a tolerable life.

The term “euthanasia” should be reserved for the compassion-motivated deliberate termination of the life of a suffering and dying person. Are there any ethical limits to the measures a patient may request, or a physician may use, to alleviate pain, suffering, and a slow process of dying? There are solid reasons why the legalization or decriminalization of euthanasia should be opposed. Now that there are practical alternatives to dying in uncontrolled pain, concentrated efforts should be made to implement programmes of palliative care. It is ethically justifiable to use every proportionate means to bring a dying patient’s pain and suffering under control. It is ethically irrelevant that a hastening of death may follow. This control of pain and suffering is not euthanasia. Consequently, a legalization of euthanasia is not necessary to guarantee doctors immunity from prosecution in such circumstances. Communication between patients, families, doctors and clinical staff should be improved so that all will know and agree on what is the right thing to do.

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**Palliative care: the wastepaper basket option**

Quality of life and comfort before death could be considerably improved through the application of current knowledge on palliative care, which is all too often ignored or regarded as a type of “wastepaper basket alternative” among treatment options. Globally, palliative care is still a neglected area and several million cancer patients suffer needlessly every day as a result. Although it is the only realistic option for most cancer patients, palliative care attracts few of the available cancer control resources.

Palliative care—an urgent but neglected public health priority

Medical knowledge today helps people to survive diseases that were previously fatal, and to live with incurable conditions for longer than ever before. Nonetheless, global estimates predict rapid increases in the number who will die from cancer and other noncommunicable diseases. What can be done to ensure that the quality of their last years is acceptable? The same care and attention now given to newborns, those who enter life, ought to be given to those who are about to leave it. By palliative care, the quality of life of the terminally ill can be significantly improved.

Globally, palliative care is a neglected area. We need political vision and leadership to ensure a multidisciplinary approach, as the problems are not only medical but also socioeconomic, social and ethical. Input from sectors of society other than the medical sector is required. Further, family members need to be supported, and their role re-evaluated, if an acceptable worldwide coverage is to be achieved.

A most important factor in palliative care is freedom from pain. WHO has taken a leading advocacy role in cancer pain relief and palliative care, with the principle that the search must be for scientifically valid methods that are acceptable and maintainable at the community level. This is exemplified by the consensus WHO established in 1982 that drugs are the mainstay of cancer pain relief and that a relatively inexpensive, easily applicable method exists. The WHO “Three-step analgesic ladder” approach towards relieving cancer pain is now widely accepted and has been used to great benefit in many countries.

WHO has made palliative care a priority in its Global Cancer Control Programme, with emphasis on support to countries that want to set up national cancer control programmes. WHO aims at making countries, nongovernmental organizations, policy-makers and the general public aware of palliative care.

In advocating “Why not freedom from cancer pain?”, WHO recommends that countries establish a triple foundation based on government policy, education, and drug availability. These three specific measures cost relatively little, but can have far-reaching effects. They are interlinked, so achievements in two areas without the third will severely limit the effect of the project. Establishment of a national policy on relieving cancer pain and success in educating the public, health care professionals and policy-makers are inadequate if the necessary drugs—especially the opioid analgesics—are not available for the patients.

National policies on pain control and terminal care have been established in twelve countries. In addition, palliative care and/or pain relief have also been included in the national cancer control policies and programmes of several other countries.

Palliative medicine evolved from the care of cancer patients who commonly suffer from the prolonged disease process before death. The knowledge and experience gained from palliative cancer care can also be applied successfully to improving the care of patients suffering from other diseases such as AIDS.

Further reading


